Integrated care for intellectual disability and multiple sclerosis

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Chapter 4

Integrated care for people with Intellectual Disability: evaluation of an experts' network

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Submitted for publication

Abstract

Background: the quality of primary health care for people with ID often seems inadequate due to a shortage of professionals familiar with the needs of this specific population. The objective of this study is to assess whether integrated care for people with ID results in adequate referrals and, as a result, in higher quality of care, adequate treatment of health care problems, detection of unrecognized and untreated health problems, and appropriate use of health care services.
Method: an experts' network was designed, available for people with ID living outside an institution. At baseline (before consulting the experts' network) patient's symptoms, pattern of referral to the experts' network and quality of care by GP and other health care professionals involved was measured. After consulting the network (T1) expectations of the experts' network, satisfaction with the experts' network, presence of symptoms and quality of care by the AVG and other health care professionals affiliated to the experts' was measured.
Results: in eight months only six patients with ID were referred to the experts' network.
Discussion: despite the initial interest in the experts' network of all those concerned, parents and primary carers hardly made use of the specialist care of the AVG. Reasons for not consulting the experts' network are uncertain, and it is not clear whether integrated care contributes to a higher quality of care for non-institutionalised people with ID.

Introduction

Due to the continuing deinstitutionalization, at the moment an estimated 67.600 of the 103.000 people with Intellectual Disability (ID) in the Netherlands live in a non-institutional setting. This means that they are living on one's own, with their parents or in group homes.[1] The transition of people with ID from institutions to the community has resulted in a shift of responsibility towards primary health care services. People with ID living outside an institution will be reliant on a General Practitioner (GP) rather than an institutional doctor for their primary medical care. However, the quality of primary health care often seems inadequate due to a shortage of professionals familiar with the needs of this specific population.[2] As a result, people with ID experience more disparities in health, shorter life spans, and poorer access to professional health care than people without ID.[3-8]

Cooperation between GPs and other health care professionals and achieving continuity of care may therefore be particularly important to correct the inadequacies in primary health care for this vulnerable population. In this respect, a coordinated integrated care approach may have advantages. Integrated care is described by Mur-Veeman *et al.* as 'inter-sectoral cooperation (coordination/networking) between care providers from both the health and social care sector in order to deliver seamless/continuous care to vulnerable people with multiple needs, as a remedy to fragmentation and discontinuity'.[9] Such an approach is required when not one single service, agency or professional identity covers all of the needs of those service users with multiple and complex problems. The essence of integrated care is that individuals receive the care services they are in need of, by the right person, when and where they need them. It is assumed that integrated care appears seamless to the service recipients without overlaps or gaps and therefore results in increased effectiveness and quality of care.[10,11] In case of ID there is little evidence that integrated care offers potential for eliminating the fragmentation and discontinuity in health care of people with ID and promoting improved effectiveness and efficiency of health care.[12]

This paper presents the results of a prospective study that was carried out in order to assess whether integrated care for people with ID results in higher quality of care, adequate treatment of health care problems, detection of unrecognized and untreated health problems, and appropriate use of health care services. The reason for this initiative was a survey in 2001 among parents and primary carers of people with ID. The results of this survey showed that parents and primary carers experienced a low continuity of care for their children. They also missed engagement of the GP with respect to psychosocial aspects of health care for people with ID. With this information we aim to provide professionals and policy makers insight in how integrated care for people with ID functions and what it produces. This may be useful in case people want to set up a comparable integrated care initiative elsewhere.[13]

Materials and Methods

Intervention

In order to improve medical care for people with ID living outside an institution in two provinces of the Netherlands (Drenthe and Overijssel), two experts' networks were established (Figure 1).

The networks were directed towards GPs, who, with reference to certain medical problems, were not able to make a diagnosis or treat a patient with ID adequately. In these cases, parents or primary carers of the patient, GPs could consult a 'physician for people with ID' (Arts voor Verstandelijk Gehandicapten (AVG)) associated with one of the networks, by telephone. During the telephone consultation the AVG decided, dependent on the health care need(s), whether the person with ID had to be referred to the experts' network or if an advice from the AVG by telephone would suffice. All professionals that committed themselves to the network were experienced in providing health care for persons with ID. When the person with ID was seen by a number of experts' network professionals, a multidisciplinary advice was formulated. When local expertise to act on the advice was present, the regular health care professionals were requested to follow the treatment advised. If not, the treatment consequently started by the professionals of the network. When the treatment was completed, the patient was referred back to the GP. With this initiative, several professionals, organisations and a health insurance company tried to improve medical care for community living persons with ID.

The establishments of the experts' networks fit with the policy of the Dutch government (Ministry of Health, Welfare and Sport) which shares the opinion that professional medical care has to be available for every person with ID, irrespective of their living situation.

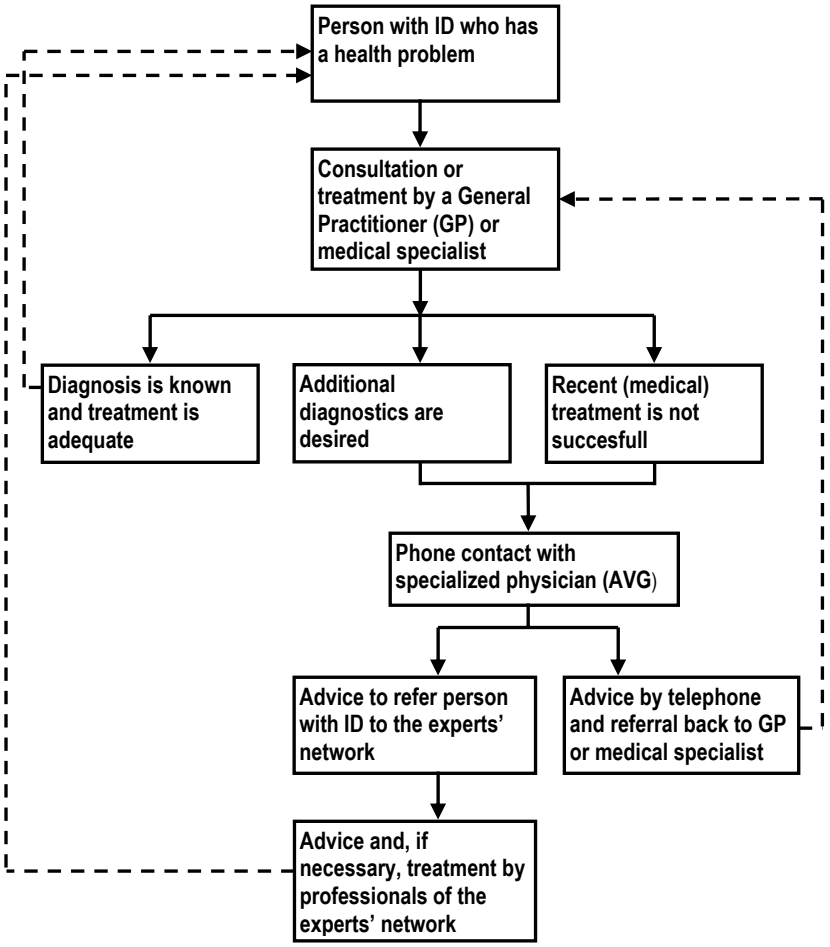

Figure 1 Procedure of consulting the experts' network

Study sample

The study sample consisted of parents or primary carers of persons with ID who were referred to the experts' network between 1 September 2004 till 1 May 2005 (n=6). Written informed consent from parents or primary carers was obtained before entry in the study.

Data collection

At baseline (before the first consultations of the AVG) parents or primary carers were sent a written questionnaire (T^0). The questionnaire focussed on:

- patient's symptoms (nature and duration of the symptoms);
- pattern of referral to the experts' network (by whom and reason for referral);
- quality of care by GP and other health care professionals involved (derived from the QUOTE-questionnaire (= QUality Of care Through the patient's Eyes).[14] This questionnaire consists of five dimensions (professional competence, relational characteristics, advice and information, contextual characteristics and result of the treatment. With reference to the present study only the first dimension (professional

competence) was applicable. This dimension includes the sub-dimensions skills and knowledge.

The data collection on behalf of the second measurement took place after consultation or treatment by the AVG of the experts' network (T^1). The questionnaire included items on:

- expectations of the experts' network;
- satisfaction with the experts' network;
- presence of symptoms;
- quality of care by the AVG and other health care professionals affiliated to the experts' network (derived from the QUOTE-questionnaire).

Results

Response

Between September 2004 and May 2005, six patients with ID were referred to the experts' network. All parents or primary carers of the six patients filled out the T^0-questionnaire. Within the eights months time frame the treatment by the experts' network of only one patient was completed. Therefore only this patient could complete the T^1-questionnaire. Demographics of the persons with ID are described in Table 1. The patients who consulted the network vary in age (range 9-56 years) and level of ID. Four of the six persons with ID live with their parents. Three persons have Down Syndrome whereas the etiology of two persons is unknown.

Table 1 Demographic characteristics of the patients with ID

Variable	**Mean ± SD**	**n**
Age (years)	21 ± 18 (range: 9-56)	
Gender:		
male		2
female		4
Living situation:		
living at home		4
foster home		1
group home		1
Aetiology ID:		
unknown		2
down syndrome		3
prematurity		1
Level of ID:		
mild		1
moderate		1
severe		3
unknown		1

Quality of care

In this study quality of care delivered by the GPs was measured by means of skills and knowledge of the GPs (Table 2).The first four statements refer to the knowledge of the GP. All but one respondents find that GPs are ill-informed about health care and developments in health care for people with ID. With reference to the skills of the GPs (the remaining eight statements) the respondents appear to be somewhat more positive, in particular with regard to the awareness of GPs of the problems, limitations and possibilities of the individual with ID, adequate referring and the strength of any advice or treatment.

Table 2 Knowledge and skills of the GPs as judged by parents and primary carers at T^0

Our GP …	*Agreement (n)**	*Disagreement (n)**
… is competent to deal with health care to people with ID	1	5
… is informed about the latest developments in health care to people with ID	1	5
… has knowledge of the rules and procedures with regard to the provision and compensation of services and adjustments	1	4
… knows which disorders often goes together with an ID	1	4
… does understand the problems of my child	3	2
… gives appropriate and useful advice	1	4
… gears the care to the abilities of my child	2	4
… places himself in my child's perception of the environment	2	2
… knows the problems, limitations and possibilities of my child	4	1
… talks to me when I feel things are going wrong	2	3
… refers my child adequately to other health care professionals or organizations	5	1
… does not force my child any advice or treatment	6	-

* Not all respondents gave their opinion

Health care problems

In Table 3 the health care problems are presented which induced the parents or primary carers of the persons with ID to consult the experts' network. Four of six patients consulted the AVG of the experts' network because of behavioral problems. With respect to three of those patients the behavioral problems existed in combination with other health care problems like psychiatric disorders or sleeping problems.

In five patients the symptoms existed for longer then half a year and in three patients the symptoms worsened in the course of time. Four of six patients were referred by the GP, however only one referral took place in consultation with the GP. Although most of the symptoms existed longer than half a year, most of the respondents judged that all referrals occurred timely.

Table 3 Patients' health care problems

Variable	n
Nature of the symptoms:	
behavioral problems	4
autism	1
sleeping problems	1
physical problems	3
psychiatric problems	1
Duration of the symptoms:	
> one year	3
> a half year	2
several months	1
The course of symptoms:	
has worsened	3
remained unchanged	1
showed variation	1
has improved	1
Referred by:	
GP	4
no referral[1]	2
Reasons for referral:	
parent or primary carer asked for referral	3
on the advice of another health care professional	2
in consultation with the GP	1
Timely referral:	
yes	4
no	1
not applicable	1

[1] people with ID can consult an AVG without being referred by a GP. They do however need an indication of the Regional Indication Organisation (Regionaal Indicatie Orgaan) and a referral letter (Kramer *et al.* 2005).

Table 4 Advice of the AVG after the first telephone consultation

Advice	n
AVG gives information about syndrome	1
AVG gives diagnostic advice	1
AVG advices to refer the patient to health care professional related to the experts' network	
‣ AVG	3
‣ gynaecologist	1
AVG advices to refer the patient to other health care professional not related to the experts' network	
‣ team physician of the patients' institute	1

Treatment of health care problems

The advices of the AVG after the first telephone consultation are presented in Table 4. With reference to four of the six persons with ID, the AVG advised to refer the patient to an AVG or to another health care professional related to the experts' network. With respect to these four patients a face-to-face consult was planned. During the first face-to-face consult all four patients were diagnosed by the AVG with: symptoms of autism and problems in handling information (n=1), affective disorder/bipolar mood disorder (n=1), fatigue of unknown origin (n=1) and severe hypothyroidism (n=1).

Because the treatment of only one person with ID was completed, we could only follow the course of health care problems of this person. The primary carer of this individual wrote in the questionnaire that the AVG had given the desired information and advice. The respondent also stated that the symptoms of the individual with ID improved after consulting the AVG.

Use of other health care professionals

Besides the GP several other health care professionals were consulted by parents or primary caregivers before the experts' network came in sight. These concerned The Regional Institute for Mental Welfare (RIAGG) (n=1), the Autism Team (n=2), several medical specialists like an ear, nose and throat specialist, a pediatrician, a neurologist and a rehabilitation specialist (n=6) and a physiotherapist (n=1).

Discussion

This study shows that parents or primary carers of the patient with ID did not make use of the service of the experts' network. This is contrary to the expectations of parents, managers, policy makers and AVGs at the start of the project and unexpected after the

thorough and extensive introduction of the experts' network. According to the literature, the introduction of a health care innovation (i.e. the experts' network) can be facilitated by several factors, like the timely involvement of all those concerned.[15] With respect to preliminary activities as to the development of the experts' network, various people from a range of backgrounds such as parents and primary carers, health care professionals and certain service organizations were installed in a feedback group. The purpose of this feedback group was twofold, namely to provide the background and context to the changes in health care to people with ID and to actively think along and advise with respect to the development of an experts' network. With respect to the actual establishment and introduction of the experts' networks all parties involved (parents and primary carers, AVGs and GPs) were frequently approached in order to advice and to facilitate the founding of the experts' network.

Another essential feature in order to facilitate the introduction of an innovation is to meet certain preconditions.[15] With respect to this project the most decisive precondition was the remuneration of the AVGs. Although AVGs get paid for consultations for which a referral is required (face-to-face consultations), there still is no formal compensation for a telephone consultation. During the present project this problem was solved by the local health insurance company by ensuring a fair reimbursement for the telephone consultations of the AVG. Although the most important hazard was now accounted for, yet the health care innovation described in this paper failed.

One explanation may be the difference in the status of health care between 2000 (start of the development of the experts' network) and 2004 (start of the introduction of the experts' network). Literature about fragmentation and discontinuity of care for people with ID mainly dates from the period 1995-2000.[12] From the development of the experts' network in 2000 onwards, several developments occurred and a number of initiatives were arranged in order to optimize medical care for people with ID in the Netherlands. One of these developments was the introduction of the specialty 'physician for people with ID' (Arts voor Verstandelijk Gehandicapten (AVG) in February 2000. However, because the AVGs were not covered by the regular health insurance company, they were only available for institutionalized people with ID. From mid-2002 onwards also for non-institutionalized people with ID it was possible to consult an AVG.

Another explanation may be found in the growing community integration of people with ID since the nineties. Perhaps in the course of time GPs got accustomed to this heterogeneous patient population with its complex health care needs and as a result gradually gain the experience necessary to deliver high-quality medical care. Following this, one can dispute the fact that today's GPs have lack of knowledge. However, a recent study of Phillips *et al.* shows that GPs still feel they are inadequately trained in areas like behavioral or psychiatric conditions, human relations and sexuality issues and complex medical problems.[16]

A third explanation why GPs hardly refer people with ID to the experts' network might be the fact that GPs are convinced that they provide the right care. When a person with ID

consults a GP for a certain health care problem, many times the GP indeed is competent to diagnose and treat the patient adequately. But in some cases, certain areas of health care may be neglected or overlooked, for example if the individual is assumed under care of another health care professional or if clinical signs are less obvious. In particular, health screening and health promotion for people with ID in general practice has been demonstrated to occur less frequently than in the general population. As a result certain health care problems commonly remain unrecognized or poorly managed.[17] As the main providers of primary health care for people with ID, GPs need to be acquainted with the specific health problems of people with ID, in order to be able to identify them.[8] In case they are not familiar with the specific health problems, GPs are unable to recognise or detect certain existing, potential or latent health problems. They possibly may therefore not feel the need to refer the patient for example to a specialist like an AVG.

A last explanation of the few referrals to the experts' network might be the unfamiliarity of the GP with the AVG. However, an essential difference between the two experts' networks largely rejects this possible explanation. The network in the province of Drenthe consisted of nine AVGs who were solely affiliated to one of the three largest intramural settings for people with ID in Drenthe. The AVGs in the other network (in the province of Overijssel) were also affiliated to an intramural institution, but next to this part-time position they also runned a GP practice. The AVGs in the province of Overijssel consequently already had their GP network and in fact, every fellow GP was aware of the fact that the GP concerned also was an AVG. However, this information did not lead to more referrals.

The aim of the present study was to assess the benefits of integrated care for people with ID. The results showed that parents, primary carers and GPs hardly consulted the experts' network. Reasons for not consulting the AVGs are uncertain, and it is not clear whether the care of the AVG contributes to a higher quality of care for non-institutionalised people with ID. As a result of the ongoing developments in health care for people with ID, a thorough update of recent care may be desirable in order to estimate the reasons and conditions to improve the quality of medical care: at what points does the care to persons with ID differ from the most desired situation and what are the impeding and facilitating factors in order to reach the desired situation? Without an analysis of recent care it is hard to determine the actions necessary to be taken in order to improve care.[15]

In conclusion, in order to improve health care for people with ID, further research is needed to reveal current health care issues. Such evaluations should, besides thorough assessment of (un)met health care needs among persons with ID, also incorporate coordination and continuity of care delivered by the services involved and communication between health care professionals. Only this information will give us the opportunity to adequately manage certain health care issues in ID and to explore if and how the AVG can contribute in the care for non-institutionalised people with ID.

References

1. The National Public Health Compass [Internet]. Bilthoven: National Institute of Public Health and the Environment; 2005 May 15 - [cited 2005 May 15]. Available from: URL: http://www.nationaalkompas.nl.
2. Braden K. Health Disparities and Mental Retardation: Programs and Creative Strategies to Close the Gap. In: *Closing the Gap. A national blueprint to improve the health of persons with mental retardation. Report of the Surgeon General's Conference on Health Disparities and Mental Retardation*. Washington DC, US Department of Health and Human Services, 2002.
3. Beange H, McElduff A, Baker W. Medical disorders of adults with mental retardation: a population study. *American Journal of Mental Retardation* 1995; 99: 595-604.
4. Lennox NG, Diggens JN, Ugoni AM. The general practice care of people with intellectual disability: barriers and solutions. *Journal of Intellectual Disability Research* 1997; 41: 380-90.
5. Lennox NG, Kerr MP. Primary health care and people with an intellectual disability: the evidence base. *Journal of Intellectual Disability Research* 1997; 41: 365-72.
6. Evenhuis HM. Mensen met een verstandelijke handicap: normale burgers, bijzondere patiënten. Aanzet tot een wetenschapsbeleid [People with intellectual disability: normal citizens, special patients. Initiative to research policy]. Inaugural Lecture, Erasmus University Rotterdam, 2002.
7. Horowitz S, Kerker B, Owens P, Zigler E. The health status of individuals with mental retardation. New Haven: Yale School of Medicine. Published by Special Olympics, Inc., 2001.
8. Jansen DEMC, Krol B, Groothoff JW, Post D. People with an intellectual disability and their health problems: a review of comparative studies. *Journal of Intellectual Disability Research* 2004; 48: 93-102.
9. Hardy B, Raak A van, Mur-Veeman I, Steenbergen M, Paulus A. Comparison and reflection. In: Raak A van, Mur-Veeman I, Hardy B, Steenbergen M, Paulus A. *Integrated care in Europe: description and comparison in six EU countries* (169-190). Maarssen: Elsevier Gezondheidszorg, 2003.
10. Mur-Veeman I, Raak A van, Paulus A, Steenbergen M. Introduction. In: Raak A van, Mur-Veeman I, Hardy B, Steenbergen M, Paulus A. *Integrated care in Europe: description and comparison in six EU countries* (9-14). Maarssen: Elsevier Gezondheidszorg, 2003.
11. Vondeling H. Economic evaluation of integrated care: an introduction. *International Journal of Integrated Care* [serial online] 2004 March. Available from: URL: http://www.ijic.org/.
12. Jansen DEMC, Krol B, Groothoff JW, Post D. Towards improving medical care for community living people with intellectual disability: possibilities of integrated care. *Journal of Applied Research in Intellectual Disabilities*. 2005. Accepted for publication.
13. Øvretveit J. Evaluating health interventions: an introduction to evaluation of health treatments, services, policies, and organizational interventions. London, Open University Press, 2003.
14. Sixma HJ, Calnan MW, Groenewegen PP, Calnan S. Quality of care from the perspective of Occupational Therapist-users. Utrecht, Kent, Maidstone: NIVEL, Centre for Health Services Studies, Kent Social Services Department. Occupational Therapy Bureau, 1999.

15. Grol R, Wensing M, Laurant M, Harmsen M. Implementatie van kennis in de praktijk. Het richtlijnen implementatie programma [Implementation of knowledge in practice. The guidelines implementation programme]. Nijmegen, Centre for Quality of Care Research, 2003.
16. Phillips A, Morrison J, Davis RW. General practitioners' educational needs in intellectual disability health. *Journal of Intellectual Disability Research* 2004; 48: 142-9.
17. Lennox NG, Diggens JN, Ugoni AM. Health care for people with an intellectual disability: general practitioners' attitudes, and provision of care. *Journal of Intellectual & Developmental Disability* 2000; 25: 127-34.